
Other:
Hollin, G orcid.org/0000-0003-4348-8272 (2017) Both maker and writer: Steve Silberman and the history of autism. Palgrave Macmillan.

https://doi.org/10.1057/s41292-017-0073-0

Both maker and writer: Steve Silberman and the history of autism.

Steve Silberman

NeuroTribes: The Legacy of Autism and the Future of Neurodiversity, New York, Penguin, 2015, ISBN: 978-1583334676, US$5.90.

Reviewed by

Greg Hollin, School of Sociology and Social Policy, University of Leeds, UK

Introduction

In December 2001 Steve Silberman published an article in *Wired* magazine called 'The Geek Syndrome' (Silberman 2001). Silberman's piece examines an apparent 'autism epidemic' in Silicon Valley and wonders if a possible explanation might be assortative mating: people preferably reproducing with people similar to themselves. The logic of the article goes as follows: Perhaps 'the geeks' who excel in the high-tech, innovation driven jobs clustered in Santa Clara are actually exhibiting sub-clinical autistic traits. And maybe, Silberman continues, novel geographical clustering makes it more likely that two people with such traits will meet each other and have children. Finally, perhaps autistic traits are both genetic and cumulative and, thus, children born in Silicon Valley will exhibit more autistic traits than either of their parents and receive a clinical diagnosis while simply representing the tip of a population to which their parents also belong.

Over 15 years since its publication, there remains an awful lot to say about 'the geek syndrome'. The first is simply to note that, for a 10-page article tucked towards the back of a magazine, it has been hugely influential. *Time Magazine* led with a story about autism in 2002 which directly drew upon Silberman's work (Nash 2002) and Silberman himself states that he still receives weekly emails about the article (Silberman 2015: 12). We're not exactly talking *Rain Man* here but in the history of popularizations of autism Silberman's article is amongst the most important piece of the new millennium.

A second thing to consider: The hypothesis that some parents exhibit sub-clinical traits associated with autism resonates with one of the most important ideas emerging at the time, chiefly that autistic tendencies are not restricted to diagnosable individuals but are, instead, spread throughout the population. One of the principle proponents of this theory is British psychologist Simon Baron-Cohen who created a questionnaire designed to test your 'Autism Quotient' or AQ (Baron-Cohen et al. 2001). The AQ treats autism in much the same manner that IQ tests treat intelligence; as a normally distributed trait present to some degree in us all (cf. Wakabayashi et al. 2006). To a greater or lesser extent everyone is, scientists such as Baron-Cohen now suggest, "a little bit autistic".

Sociologically, Baron-Cohen's research is interesting in that it encourages all of us – and not only those with a diagnosis – to think of ourselves in new ways. Silberman's piece significantly launched this hypothesis into the world: Baron-Cohen's work is discussed, Baron-Cohen himself is given a 4-page interview, and in the middle of the geek syndrome is a full page spread devoted to the aforementioned and recently published AQ test. Readers are invited to 'take the test', measure 'the extent of [their] autistic traits', and understand themselves in new ways. It is impossible to know how many readers have taken *Wired's* AQ test but it will be many millions. The UK television programme *Embarrassing Bodies* hosts an online 'Mind Checker' which includes an online version of the AQ that has been taken over 1.5 million times as of August 2017. Given *Wired's* readership, the prominence of Silberman's article, and the fact that their version of the AQ remains among the first search returns on Google it is inconceivable that the figure associated with *Wired's* version will be anything but significantly higher.

As Michelle Murphy has discussed, the fact that surveys like the AQ are so easy to complete, reproduce, and distribute gives them an unparalleled capacity to assemble a 'commonality out of experience' (Murphy 2006: 143). By encouraging readers of *Wired* to 'take the test' it seems highly likely that Silberman's article brought autism to millions of new spaces and subjects and, sociologically, altered the contours of what autism is in highly significant ways. The point that I am making here is that Steve Silberman's previous work is itself part of the fabric of autism and, thus, when discussing his new book *Neurotribes: The legacy of autism and how to think smarter about people who think differently* a reviewer is in the unusual position of needing to be attuned not only to the history which is being told but also, potentially, the history which is being made.

Beyond the geek syndrome

Given the above, it is interesting to note the manner in which Silberman positions *Neurotribes* in relation to the geek syndrome. *Neurotribes* begins by threatening to be a sequel: The back cover

proudly proclaims it to be 'following on from his groundbreaking article' while the introduction is entitled 'beyond the Geek Syndrome'. The narrated relationship between book and article, however, turns out to be complicated. Silberman does not disown the assortative mating hypothesis of the geek syndrome and there is one cryptic passage where, in conversation with psychologist Lorna Wing, it is casually suggested that 'perhaps the advent of the Internet has accelerated "an evolutionary tendency"' for autism; an argument which seems to take us back towards assortative mating within contemporary, technologically dominated, environments (Silberman 2015: 422)[1]. The tone in *Neurotribes* is not that his previous work is incorrect; it is, rather, that determining what causes autism is simply no longer a priority.

When writing the geek syndrome, Silberman tells us that he embraced the hype of the new genetics; it was only a matter of time before the underpinnings of autism were discovered and the suffering of those individuals who were disabled and clinically diagnosed was alleviated, presumably through an intervention at the level of their biological make-up. Today this hope is untenable. Billions of dollars have been spent uncovering thousands of genes, de novo mutations, and epigenetic factors associated with autism and yet there is no sign of any therapeutic advancement. Meanwhile, comparatively little has been spent on 'addressing the day-to-day needs of autistic people and their families' (Silberman 2015: 15) and, perhaps because of this, 'Up to three quarters of all autistic children in the United States receive some form of alternative treatment' (Silberman 2015: 70) which is often unregulated, dangerous, and a part of the legacy of the MMR vaccine scandal. I was reminded through this of Andrew Scull's recent phrasing: the wager that *practical* payoffs would follow from understanding conditions like autism through a biomedical lens is largely 'a bet we have yet to collect' (Scull 2015: 15). Between writing the geek syndrome and *Neurotribes*, Steve Silberman seems to have reached the same conclusion.

Neurodiversity: A sociology

And so Silberman searches for a different story and the story that he finds is that of neurodiversity. Although it is not articulated in these terms, the neurodiversity movement for Silberman re-iterates the core tenets of the Social Model of Disability (SMD); autistic individuals are different not deficient, have amazing abilities that can profoundly improve society and, perhaps most importantly, '...the cure for the most disabling aspects of autism will never be found in a pill, but in supportive communities' (Silberman 2015: 17). Silberman is basically right in this regard. It is

[1] There is a tension, however, which is present throughout the book. Silberman's continual description of individuals with Asperger's as being members of a 'lost [neuro]tribe' inevitably conjures a, perhaps problematic, image of distance and separation that runs against the grain of a quantified, distributed autism.

important to remember that the SMD was never meant to offer some profound ontological commentary, indeed 'it did not emerge from the academy. It was born of resistance on the part of disability activists,' and progressed by self-advocacy groups (Beckett & Campbell 2015: 271). As Silberman stresses in chapter 11 of *Neurotribes* the same situation is true for neurodiversity. In political terms, the SMD/neurodiversity is a force for good and, frankly, the lives of many with autism would be better if we all just went with it.

Silberman illustrates the benefits of a neurodiverse perspective well by detailing a series of beautiful stories of autistic individuals shaping the world while their friends and families provide the supporting environments that allow them to flourish. Some of these people - like Leo Rosa who stars in the chapter *the boy who loved green straws* and Bill, an inspiration for the film *Rain Man* - have been diagnosed with autism. Others - like scientist Henry Cavendish and the inventors and science-fiction aficionados described as *the princes of the air* - have been retrospectively diagnosed by Silberman. Rather than provide another iteration of tired arguments about the rights and wrongs of retrospectively diagnosing historical figures, it seems enough to say here that these are well told and empathetic stories which ably demonstrate the benefits of 'thinking smarter about people who think differently,' as the title has it. From a scholarly perspective, it is perhaps more interesting to dwell on the answer to a corollary question posed by Silberman: Given the obvious benefits, why did something akin to a neurodiversity perspective take fifty or sixty years to develop after the naming of autism and why is yet to be fully embraced by society at large? For Silberman the answer is found in history.

Neurodiversity: A history

Contemporary narratives generally recognise two figures as the discoverers of autism: Leo Kanner and Hans Asperger. Kanner and Asperger conceptualised autism quite differently to one another, however. Kanner had a tendency to blame mothers for their children's condition and conceptualised autism as a 'rare, inevitably devastating, and homogenous disorder' (Silberman 2015: 41). For Asperger, meanwhile, autism:

> '…was "not at all rare," was found in all age groups, and had a broad range of manifestations, from the inability to speak to an enhanced capacity for focusing on a single subject of interest for an extended period of time without distractions.' (Silberman 2015: 130)

According to Silberman, Asperger recognised something akin to neurodiversity (Silberman 2015: 128), the strengths of his patients, and the sheer numbers of people requiring support.

Asperger, therefore, saw autism almost precisely in the terms that Silberman sees as most beneficial for today's society. Unfortunately, for most of the twentieth century it was Kanner's conceptualization that held sway and, according to Silberman, it is precisely this which prevented neurodiversity from flourishing. It was only when Asperger's work reached the Anglosphere in the 1980s, thanks to translations by Lorna Wing, that it became possible to recognise the full spectrum of autistic conditions and to move away from the tragedy model inherent in Kanner's work.

There is also an important sub-plot to this story. The longstanding assumption has been that Kanner and Asperger reached their conclusions independently and that Kanner's work became dominant due to the fact that Asperger wrote in German and remained unknown to English-speaking audiences. In an important finding, Silberman demonstrates that this was almost certainly not the case. While there had previously been claims of plagiarism on Kanner's part (e.g. Fitzgerald 2008), Silberman's archival research has found proof and a mechanism. Two individuals who worked with Asperger in Vienna – psychologist Anni Weiss and psychiatrist Georg Frankl – ended up working for Kanner at John Hopkins in Baltimore (Silberman 2015: 167). Given these links, Silberman demonstrates, it is not that Kanner did not know of Asperger's work but that he deliberately attempted to erase his contribution.

This is more than historical book-keeping for Silberman:

> 'Until these inaccuracies in the time line are corrected, they will continue to hamper our ability to make wise choices about the kinds of research and societal accommodations that would be beneficial to autistic people and their families.' (Silberman 2015: 15)

The central narrative of *Neurotribes* is thus completed and the figures fall into place: Neurodiversity is society's way forward; Asperger recognised neurodiversity; Kanner actively suppressed Asperger; Kanner's acts entailed that neurodiversity has remained underacknowledged and he therefore has a significant degree of culpability for the suffering of autistic individuals and their families.

Writing and making history

What to make of this story? As a *writer* of history, the finding of conclusive links between Kanner and Asperger is a novel and important one. Chloe Silverman, whose own history of autism covers the research in question (Silverman 2012), has noted that these links have been missed and praises Silberman's descriptions of Asperger's early work as among the strongest produced (Silverman 2015: 1113). For academic audiences, this will almost certainly be Silberman's most significant contribution, although the profundity will differ depending upon theoretical persuasion.

Beyond this, Silberman's assertion that if only Asperger had been acknowledged in the 1940s we'd be living in a tolerant, neurodiverse world seems optimistic in the extreme. Tolerance for minorities, including those with disabilities, hardly seems to be at an all-time high. The saint (Asperger) and sinner (Kanner) narrative also seems a bit forced. Kanner's publishing practices do seem to leave something significant to be desired but it is peculiar that, for Silberman, this seems to overshadow the fact that Weiss and Frankl arrived in Baltimore because Kanner and his wife were acting as 'an unofficial immigration agency for Jewish doctors, nurses, and researchers' (Silberman 2015: 163, 168) fleeing the Nazis. The narrative is made even more tortuous by the fact that Asperger stayed to work within Nazi occupied Austria. Silberman argues that Asperger was anti-Nazi and used his position of influence to save autistic children from eugenic procedures (Silberman 2015: 129). Yet an even newer (and longer) text on the history of autism, the Pulitzer nominated *In a Different Key* (Donvan & Zucker 2017), paints a far more sinister picture of someone who actively contributed to the regime. In a review of that book, Silberman makes clear that he will edit subsequent editions of *Neurotribes* to reflect the fact that Asperger 'signed a letter of referral effectively condemning a little girl with encephalitis named Herta Schreiber to death in a Vienna rehab facility that had been converted into a killing center by Asperger's former colleague, Erwin Jekelius' (Silberman 2016). This is one of few arguments from *In a Different Key* that Silberman claims he has been able to independently verify, and while he may well be right to continue to stress Asperger's positive contributions the same luxuries are rarely afforded to Kanner.

But what about Silberman as a *maker* of history? I have already noted that I believe the inclusion of the AQ test within *Wired* to be a significant moment in the history of autism, opening the possibility for all manner of individuals to understand themselves through the language of autism. In *Neurotribes* Silberman actually dwells on a comparable moment (Silberman 2015: 277): the decision by parent-scientist Bernard Rimland to include a novel clinical questionnaire, subsequently returned *en masse* by parent-readers, as an appendix to his bestselling book *Infantile Autism* (1964). The inclusion of these questionnaires changed the course of history, exercises in popular epidemiology (Murphy 2006) which brought together diverse people and changed perceptions of space.

There does not appear to be anything as radical here, although perhaps we are too close to the moment of publication to know for certain. That said, Silberman has not lost his knack for finding an audience since publishing 'the geek syndrome'. *Neurotribes* is a New York Times best seller and won the 2015 Samuel Johnson Prize for non-fiction – one of the most prestigious literary awards

in the world[2]. Like the geek syndrome, then, *Neurotribes* will likely encourage more people to think about autism and the way in which autistic individuals are treated. In this regard Silberman, with his empathetic message of acceptance and accommodation, may be just the messenger we need.

Greg Hollin is a lecturer in the School of Sociology and Social Policy, University of Leeds. His research on autism has been published in Biosocieties, History of the Human Sciences, Science as Culture, and elsewhere.

References

Baron-Cohen, S. et al., 2001. The Autism-Spectrum Quotient (AQ): evidence from Asperger Syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 31, pp.5–17.

Beckett, A.E. & Campbell, T., 2015. The social model of disability as an oppositional device. *Disability & Society*, 30(2), pp.270–283.

Donvan, J. & Zucker, C., 2017. *In a Different Key: The Story of Autism*, London: Allen Lane.

Fitzgerald, M., 2008. Autism: Asperger's syndrome—history and first descriptions. In J. Rausch, M. Johnson, & M. Casanova, eds. *Asperger's Disorder*. New York: Informa Healthcare, p. 400.

Macdonald, H., 2014. *H is for Hawk*, London: Vintage Books.

Murphy, M., 2006. *Sick Building Syndrome and the Problem of Uncertainty: Environmental Politics, Technoscience, and Women Workers*, Durham & London: Duke University Press.

Nash, J.M., 2002. The secrets of autism. *Time Magazine*, pp.46–56.

Rimland, B., 1964. *Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behaviour*, New York: Appleton-Century-Crofts.

Scull, A., 2015. *Madness in Civilization: From the Bible to Freud, from the Madhouse to Modern Medicine*, Princeton and Oxford: Princeton University Press.

Silberman, S., 2015. *Neurotribes: The legacy of autism and how to think smarter about people who think differently*, Sydney: Allen & Erwin.

[2] Interestingly, despite being billed as the first 'popular science' book to win the prize, *Neurotribes* was actually the second consecutive winner to concern itself (broadly) with the sociology and history of science, following hot on the heels of Helen Macdonald's *H is for Hawk* (2014).

Silberman, S., 2001. The Geek Syndrome. *Wired Magazine*, pp.175–183.

Silberman, S., 2016. Was Dr. Asperger a Nazi? The question still haunts autism. *Shots: Health news from NPR*. Available at: http://www.npr.org/sections/health-shots/2016/01/20/463603652/was-dr-asperger-a-nazi-the-question-still-haunts-autism [Accessed August 11, 2017].

Silverman, C., 2015. Review: NeuroTribes: The Legacy of Autism and the Future of Neurodiversity. *Anthropological Quarterly*, 88(4), pp.1111–1121. Available at: https://muse.jhu.edu/journals/anthropological_quarterly/v088/88.4.silverman.html.

Silverman, C., 2012. *Understanding Autism: Parents, Doctors, and the History of a Disorder*, Princeton, New Jersey: Princeton University Press.

Wakabayashi, A., Baron-Cohen, S. & Wheelwright, S., 2006. Are autistic traits an independent personality dimension? A study of the Autism-Spectrum Quotient (AQ) and the NEO-PI-R. *Personality and Individual Differences*, 41(5), pp.873–883.